



30 years of service to those affected by chronic kidney disease.

Lori Hartwell
Founder/President

December 14, 2023

Wendy Rodgers, M.Ed, MPH
Chairman of the Board

To: Battelle (CMS Contractor for Measures)

Lana Kacherova, RN
Treasurer

Re: CMS-3742-P: ESRD Dialysis Patient Life Goals Survey (PaLS)

Joanna Galeas Lee
Secretary

I am writing as the Founder and President of the Renal Support Network (RSN). RSN empowers individuals with kidney disease to take an active role in their care and collaborate with healthcare professionals and other stakeholders to receive the best possible treatment, enabling them to live fulfilling lives. I have personally been living with kidney disease since the age of two (1968) and spent 13 years on dialysis.

Board Members:

Lubna Akbany, RD
Kathleen Baldwin, PhD
Kristen Cisneros, RN
Marlene De Vera, RN
Joanna Galeas Lee

RSN advocates for patient-reported outcome measures that are meaningful and effective in enhancing the experience of individuals undergoing dialysis. However, we fail to see how the "Life Goals" measure accomplishes this objective. In order to pursue life goals, one must first be in good health and possess financial and emotional stability.

Mark Hanudel, MD, MS,
FASN

Lori Hartwell

Dean Hartwell, JD

Jill Heydorff

Lesley Holden, RN

Lana Kacherova, RN

Robert M. Klein

Charlene Lafontant

Madeline Pahl, MD

Wendy Rodgers, M.Ed, MPH

David Trujillo

Rafael Villicana, MD

Susan Vogel, MHA, RN,
CNN

We perceive the proposed life goal measure as potentially harmful for people on dialysis. It brings back memories of life-and-death committees from the 60s, where individuals were chosen based on their perceived value to society. The connection can easily be made that someone without life goals may not be deemed valuable. Moreover, those without life goals are likely experiencing poor health or depression. It's well documented that living with a serious chronic illness can lead to anxiety and depression.

The survey asks patients to share their life goals with a member of their dialysis team by checking off boxes representing various goals such as being able to work, spending time with loved ones, pursuing education or independence, watching children/grandchildren grow up, taking care of family responsibilities, engaging in hobbies/activities, feeling like a regular person rather than someone on dialysis, traveling, or specifying other personal goals. The response "feeling like a regular person rather than someone on dialysis" is particularly bothersome and many of our members were uncomfortable with that response.

We reached out to our members who shared additional responses beyond what was included in the survey options:

An illness is too demanding when you don't have hope!
– Lori Hartwell, RSN Founder and President

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- Being able to pay bills
- Not burdening family
- Owning a reliable car
- Finding a partner/spouse
- Having safe housing
- Avoiding reliance on public transportation
- Receiving a transplant
- Alleviating depression
- Moving out of parents' home
- Owning a pet

We are deeply concerned about a survey that focuses on measuring the "perceived life goals" of individuals on dialysis. How will this information be used to improve their care? When will it be asked? What actions will the dialysis staff take based on these survey results? Will there be follow-up to assess if patients achieve their goals? We frequently receive calls and emails from individuals on dialysis who face major challenges regarding housing, food security, and transportation, seeking assistance. By asking these questions, the dialysis facility may inadvertently raise expectations for potential support, leading to strain in patient-professional relationships.

Additionally, we question what outcomes can be derived from this survey. If an individual has a positive goal, will their treatment be considered successful or changed? How does this survey contribute to improving overall care? Conversely, if someone has a negative goal, how will their treatment be modified?

We have heard that the goal of this measure is to help individuals realize their life goals and potentially offer them home therapy options that align with their lifestyle. We agree with that goal of helping patient choose the right treatment for their lifestyle, but do not believe this is the right approach for the reasons mentioned. Also, RSN remains uncertain about how this information will truly enhance patient care. It is important to consider that patients often experience survey fatigue when they do not receive any feedback.

The primary responsibility of a dialysis facility should lie in ensuring proper treatment. When patients receive appropriate dialysis treatment and subsequently experience reduced fatigue and improved wellbeing, they can then begin contemplating personal life goals.

As an alternative patient-reported outcome measure approach:

CMS should consider implementing a reporting measure that ensures each patient has a voice during every dialysis treatment session. For instance, after each session, patients could answer a simple question regarding whether they felt (a) not at all bothered; (b) somewhat bothered; (c) moderately bothered; (d) very much bothered; or (e) extremely bothered during the treatment.

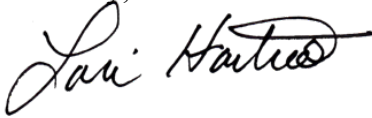
Renal Support Network

If patients indicate any level of botheration or discomfort through the initial question, a series of additional questions could be asked to identify specific difficulties they may have encountered during the treatment, such as access problems, low blood pressure, crashes, cramping, or other relevant indicators.

Collecting this information may assist healthcare providers in understanding why patients might not complete their entire treatment or miss sessions altogether. A brief and structured conversation with the patient can also provide valuable insights for physicians and facility managers to assess whether the patient is tolerating the treatment well or if adjustments need to be made before a major issue arises. The survey results can also offer guidance on whether an alternative dialysis option would suit a patient better and provide real time information to get their treatment right.

Please let me know.

Sincerely,

A handwritten signature in black ink that reads "Lori Hartwell". The signature is written in a cursive style with a large, sweeping initial "L" and a long, horizontal flourish extending to the right.

Lori Hartwell
President/Founder